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HIV EMERGENCY RELIEF GRANT PROGRAM

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Mr. KENNEDY, from the Committee on Labor and Human Resources, submitted the following

REPORT

[To accompany S. 2240]

The Committee on Labor and Human Resources, to which was referred the bill (S. 2240) to provide emergency assistance to localities hardest hit by the HIV epidemic and provides grants to states for the development, organization, coordination, and delivery of health care and support services to individuals and families with HIV disease in urban and rural areas, having considered the same, reports favorably thereon with an amendment and unanimously recommends that the bill as amended do pass.

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I. DEDICATION

This legislation is dedicated by the Senate Labor and Human Resources Committee to the memory of Ryan White who died on April 8, 1990 after a six year battle against AIDS. Beginning at the age of 13, Ryan valiantly fought not only the human immunodeficiency virus itself but also fears about AIDS that were based on ig-

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norance and senseless discrimination against people with AIDS and HIV disease. With dignity, patience and almost unvarying good cheer, Ryan White introduced to people across America and across the world a face of AIDS that caring human beings could not turn their back upon. First through his courageous fight to be allowed to go to school with his peers, then through his tireless efforts to educate and explain the realities of his illness, young Ryan White changed our world. By dedicating this legislation to Ryan, the Committee affirms its commitment to provide care, compassion and understanding to people with AIDS everywhere. Ryan would have expected no less.

In memory of Ryan White and the 70,000 Americans who have lost their lives to AIDS. And with hope for all people living with AIDS.

II. Introduction

On April 4, 1990, the Committee on Labor and Human Resources, by a vote of 16–0, ordered favorably reported S. 2240, the Comprehensive AIDS Resources Emergency (CARE) Act of 1990, with an amendment in the nature of a substitute. At that time, the Committee dedicated the bill to Ryan White and to people with AIDS everywhere.

The bill is sponsored by Senator Edward M. Kennedy, chairman of the Committee and Senator Orrin G. Hatch, ranking Minority Member, and co-sponsored by Senators Cranston, Hatfield, Bentsen, Wilson, Moynihan, D'Amato, Adams, Chafee, Kerry, Simon, Sarbanes, Riegle, Inouye, Johnston, Dodd, Lautenberg, Metzenbaum, Glenn, Pell, Bradley, Gore, Mikulski, Lieberman, Specter, Matsunaga, Packwood, Graham, Wirth, Burdick, Mitchell, Levin, Kohl, Bingaman, Sasser, Jeffords, Dole, Cohen, and Fowler.

III. Hearings Summary

The Committee on Labor and Human Resources began its exploration of the health care needs of individuals and families with AIDS and HIV infection in January, 1987. Since that time, the Committee has held more than eight hearings and heard from a wide range of public health/government officials at all levels, health care providers, AIDS advocates, and people with AIDS themselves.

In January 1987, Senator Kennedy declared AIDS a "health disaster", the severity of which may surpass "any disease in history" and stated that the federal government would need the "discipline to continue to give this crisis [its] highest priority and to provide resources and national leadership commensurate with that priority." Senator Hatch added that people with AIDS "need our support. They need our compassion. And they need to have treatment options available."

Toward that end, in May 1987, the Committee heard from the health commissioners from New York City and San Francisco. Each took the opportunity to sound the alarm and warn the Committee of the AIDS disaster that had hit their cities and the growing potential for system collapse. Dr. Joseph called for a "moonshot, war time footing approach to federal resource commitment"

and Dr. Werdegar called such a commitment, "long overdue." The National Academy of Sciences testified that AIDS had already "grievously overburdened hospitals and other facilities in urban centers" and cautioned that in the next few years, it would "engulf facilities not [then] familiar with AIDS." The Academy joined the Visiting Nurses Association and others in calling for the development and delivery of home and community based services for people with AIDS.

In July, 1988, Admiral Watkins, chair of the Presidential Commission on the HIV Epidemic, reported to the Committee the results of a year long investigation of the federal battle against AIDS. The Watkins Commission recommended the creation of a continuum of care for people with AIDS that was more responsive and cost effective than current overutilization of acute care facilities.

Finally, in four different hearings in 1988 and 1989, the Committee explored the policy options for piecing together a system of health care and support services for people with AIDS. From Washington, DC to Boston, and from the South Bronx to Sparta, Georgia, the Committee has re-affirmed the need for decisive federal action. It is with this blueprint for action in mind that S. 2240 was developed.

IV. Need for Legislation

GENERAL BACKGROUND

As of March 31, 1990, over 128,000 cases of AIDS had been reported to the Centers for Disease Control. Over 78,000 Americans have died of the disease—nearly as many as died in battle in the Korean and Vietnam Wars combined. Yet the full impact of the HIV epidemic has not yet been fully felt. The Nation will continue to experience rapid growth in reported AIDS cases for at least the next several years. While the first 100,000 cases were reported from 1981 to 1989, another 50,000 are expected to be diagnosed in 1990 alone. By 1991, AIDS will far exceed all other causes of death for people ages 25 to 44. This acceleration is virtually guaranteed to produce incredible economic and health care system stress—both in urban centers, where the HIV epidemic has raged for nearly a decade, and in smaller cities and rural areas where the numbers are now growing most significantly.

A reality of next decade has been cast, and even if further transmission of the virus were to halt today, there would still be an overwhelming disaster both unfolding daily and steadily brewing. Diagnosed AIDS cases constitute only a fraction of the problem. Accoridng to recent estimates, nearly 1 million Americans are already infected, most of whom, in the absence of medical intervention, will progress to full blown AIDS. Hundreds of thousands of persons who are HIV infected will require health care and support services long before they meet the official criteria for a diagnosis of AIDS. This crisis—referred to as a "medical earthquake" by Mayor Art Agnos, chair of the US Conference of Mayors AIDS Task Force, and a "tidalwave of health care needs" by Dr. June Osborn, chair of the National Commission on AIDS—will present an enormous challenge to our health care system in the decade to come.

In the early years of the HIV epidemic, the major focus of public policy was on research, public education, and other measures. Even today, more than 93% of the President's FY91 AIDS budget is dedicated to biomedical research, surveillance, and prevention. While these concerns remain important, the growth of the epidemic has brought another critical dimension to the forefront: the burgeoning need for adequate medical care and support services for individuals and families with HIV disease in both urban and rural areas. Science is making steady progress in developing new treatments for HIV disease, therapies that can help slow the progress of the virus itself or fend off some of the opportunistic infections associated with the disease. However, these treatments are, in the main, expensive and often unaffordable. In addition, a comprehensive continuum of services designed to reduce the excessive cost of acute care, is both unavailable and nonreimbursible. Already there is beginning to evole a two-class system of care for persons with HIV disease: those who can afford to pay for services may benefit from early treatment and delay the onset of AIDS versus those who have no money and therefore must delay until acute illness strikes and there is little that can be done.

THE COSTS OF HIV DISEASE

According to the Agency for Health Care Policy and Research, by 1992 treatment costs for individuals and families with HIV disease could be as high as $13 billion from all payor sources. While these sums are high, they represent less than 3% of a projected $700 billion in national health expenditures in 1992. At least in the short term, the problems presented by AIDS are not seen in the totals, but in the way these costs are distributed. The burden of providing care to persons with AIDS has fallen disproportionately on particular geographic areas, institutions, and payers. While the stress is greatest in the urban centers where the epidemic first took hold, the problems are also growing in smaller cities and in rural areas.

Who is paying for the care persons with AIDS? Early studies found that private health insurance was covering 40% to 60% of total AIDS care costs. Medicaid, the Federal-State health program for low-income persons, covered an additional 20% to 30% while Medicare paid only 1% to 3%. The most recent comprehensive study, however, has found that Medicaid's share is rising, to as much as 44% of total national AIDS care costs, while the share paid by private insurance has dropped to 29%. Meanwhile, the percentage of person with AIDS who have no insurance at the time they need acute and long term care has reportedly grown to 25%. We are witnessing a shift from private to public financing and an increasing reliance on charity care.

These cost trends reflect changes in the populations affected by the HIV epidemic. The most rapid increases in reported AIDS cases are among intravenous drug users, women, and children. A disproportionate number of the new cases are members of low-income minority communities. They are less likely to have employer-based or other private coverage and more likely to qualify for Medicaid from the onset of the disease. The demographic changes, however, have been accompanied by geographic diversification. As the epi-

demic moves into the South and Midwest, more restrictive Medicaid eligibility requirements in many States exclude many persons with AIDS. For example, one study found that Medicaid covered just 18 percent of persons with AIDS in the South, while 48% had no insurance at all.

Congress has attempted to make private insurance more available to persons with HIV disease or other disabilities by allowing them to continue purchasing coverage through their employer groups after they are no longer able to work. However, because AIDS has generally affected young adults with little or no savings, many persons may be unable to afford the continued insurance once their employment has been terminated.

The shifts in the populations needing services have not only reduced the financial support for HIV care from insurers and other traditional sources, but have also contributed to nonfinancial barriers to care. Increasingly, HIV disease is affecting the groups that have traditionally lacked access to primary health care and needed support services. For these individuals and families, who have no doctor and no means of payment, access to essential services is gained, if at all, through the emergency rooms of the few hospitals in each community that will accept them. These include not only intravenous drug users, women and children in the inner cities, but also persons with HIV disease in rural areas, where the growth in the epidemic is now rapid.

HIV DISEASE IN URBAN AREAS

The Public Hospital Crisis. While the HIV epidemic presents new challenges to health resources throughout the Nation its most serious impact is currently concentrated in a few areas. Just 13 cities account for 70,611 diagnosed AIDS cases or 55 percent of all cases reported. For nearly a decade, these urban centers have seen the numbers of diagnosed AIDS cases steadily increasing, the cost in human lives steadily mounting, and the level of HIV health care services provided increasingly incapable of meeting the growing demand.

Within these cities and urban counties, a disproportionate share of the burden is being borne by a handful of municipal hospitals. In a recent survey done by the National Public Health and Hospital Institute, 5 percent of hospitals—mainly public, voluntary and inner city teaching hospitals—accounted for half of all treatment provided to persons with AIDS. This concentration of AIDS care in a few hospitals is threatening to overwhelm these providers financially and limit their ability to treat other patients, bringing them to the brink of rationing. Public hospitals average a loss of nearly $200 per day per AIDS patients—more than 5 times greater than the loss of non-AIDS inpatient days.

This largely uninsured, very sick population is being drawn to these essential urban hospitals at a time when a variety of other forces are placing increasing pressure on these same facilities. Growing competition and pressure for discounts from insurers have led some private hospitals to cut back on charity care, increasing the burdens on the public hospitals. These are the same institutions that have, for generations, provided essential services to a va-

riety of vulnerable populations including the poor, the elderly, the chronically ill and mentally ill. Currently, these hospitals are facing, not just an influx of AIDS cases, but the pressing needs of the homeless and the tragic consequences of drug abuse, including drug-related violence. As a result, there are urban areas where the municipal health care system is nearing collapse.

The problems of New York City have been most widely publicized: overcrowding in the public hospitals is sometimes so intense that patients admitted through the emergency department lie in hallways for days, sometimes more than a week, waiting for a room. According to the New York City Department of Health, 70% of people with AIDS enter the hospital through the emergency room. At one hospital in Brooklyn in 1989 as many as 80 percent of available beds were occupied by patients with HIV-related problems. A city task force found that, while persons with AIDS were occupying 1,746 beds in early 1989, the number of beds needed would more than double to 4,020 by 1993. Other cities' public hospitals are facing comparable problems. Jackson Memorial Medical Center in Miami provides 60 percent of the AIDS-related inpatient care for the area. Parkland Memorial Hospital treats 50 percent of the AIDS cases in the Dallas area, and draws more patients from surrounding areas. The proportion of persons with AIDS relying on public hospitals ranges from 40 percent in Los Angeles to 70 percent in Boston and San Juan.

The hospital crisis is further compounded by the absence of comprehensive outpatient services. After extensive study, the American Hospital Association stated in a recent report entitled "Beyond the Hospital Door":

> For those people who wait weeks for a blood test, for those with severe physical symptoms who must wait weeks for a clinic appointment, and for those who will die in the street because there are too few shelters for someone dying of AIDS, community services are of critical importance. The network of services existing for people with AIDS is extremely spotty. Overall, all types of community services are less available for people with AIDS than they are for individuals with other types of chronic and fatal illnesses.

ALTERNATIVES TO INPATIENT CARE

While appropriate outpatient services could reduce the need for costly inpatient care for people with HIV disease, a recent GAO study confirmed that home and community-based services were not available to people with AIDS who needed them because both capacity and insurance coverage were extremely limited. For example, Boston's ambulatory clinic system has a six week waiting list, and Philadelphia has no organized ambulatory care system at all. A report issued by the National Public Hospital Association entitled Crisis on the Frontlines documents that hospitals lose 86 cents for every $1.00 of outpatient services provided.

Therefore, patients with HIV disease often remain for weeks in very costly hospital beds, although no longer requiring acute care, because no alternative treatment is available. This not only overtaxes the acute care system but can erode patients' quality of life

by keeping them in a dependent state. The Committee was told, while on a site visit in New York City, that approximately 10% of hospitalized AIDS patients could be released if there were community-based care systems in place.

Patients requiring the level of services provided by nursing homes have faced continuing problems in obtaining access to care. Some facilities are afraid of accepting individuals with AIDS. Others may refuse patients who lack private financial resources or private health insurance, because Medicaid reimbursement is well below their usual charges. Finally, some nursing homes may simply not be equipped to deal with the special needs of persons with AIDS, particularly those suffering from AIDS related dementia or those addicted to drugs. Whatever the reason, the shortage of so-called step down beds is critical. Only 4 nursing home beds are available to persons with AIDS in all of Illinois, while as many as 335 may be needed in Chicago alone by 1994. Only one nursing home in Houston and two in Washington will accept persons with AIDS. In Newark no beds are available, while as many as 200 are needed in 1990. In New York City, only 159 beds out of 35,000 are accessible to people with AIDS. Congress has provided very limited support for the development of long-term care facilities for persons with AIDS: just $4.4 million was appropriated for this purpose in FY1990.

Not all patients need nursing home care. Many could remain at home, with adequate health care and social support services. Comprehensive community-based and home care systems in San Francisco and elsewhere are reported to have dramatically reduced total per patient costs while at the same time providing a more appropriate level of care. Both the Federal Government and private sources such as the Robert Wood Johnson Foundation have supported efforts to develop similar systems elsewhere. Public Law 100-607. The Omnibus Health Authorization Act, authorizes up to $100 million in formula grants to States, for home and community-based service programs. However, the authorization for these grants extends only through fiscal year 1990.

HIV DISEASE IN RURAL AREAS

While HIV disease remains most heavily concentrated in the Nation's urban areas, and especially in the inner cities, the number of new cases diagnosed in similar smaller cities and rural areas is growing. Cases outside metropolitan areas accounted for 18.5 percent of new AIDS cases reported in the 12 months ended March 1990, compared to 16.1 percent in the preceding 12 months. In 1989, the Centers for Disease Control reported a 5 percent increase in diagnosed AIDS cases in metropolitan areas with populations over 500,000 and a 37 percent increase in rural areas. The Atlanta Journal and Constitution reported a tripling of AIDS cases in Georgia over the past two years and noted that for the first time, the spread of AIDS in rural areas and small towns was keeping pace with the increase in Atlanta—with Macon experiencing a 400 percent increase. AIDS cases more than doubled in areas such as Gary, Indiana, Lubbock, Texas, Biloxi, Mississippi, and Portland, Maine.

Many persons who have moved to large cities and contracted HIV disease there have returned home to be cared for by their families in smaller cities and towns. As reported in the Jackson Daily News, "AIDS has come home to Mississippi—often times to die. Once perceived to be a plague affecting other people—AIDS is invading communities at every crossroads." This movement is not reflected in standard statistics, which are based on place of initial AIDS diagnosis and which are masking an urgent need for better HIV health care and support services outside the large metropolitan areas.

Some of the problems raised by HIV disease in rural areas are the same as those being confronted in our largest cities, while others are unique and reflect the general barriers to medical care in rural areas.

As in urban areas, rural areas suffer from a lack of nursing homes or other long-term care facilities willing or able to accept persons with HIV disease. Alternatives, such as home and community-based care networks, may be even harder to develop, because of a scarcity of resources and a population in need too scattered to support a centralized system. Similar obstacles may be faced by efforts to develop coordinated outpatient services programs.

Persons with HIV infection outside urban areas, and the health care providers who treat them, may be less aware than those in urban areas of the newest evidence on the benefits of early diagnosis and treatment of HIV infection. There is a need for outreach and educational activities to ensure that the advances in recent years are made available to all infected persons, not just those in urban areas.

Finally, small rural hospitals and other rural providers may not be able to provide the highly specialized services required by some persons with HIV disease. Because many small communities are ill equipped to provide comprehensive services, some patients are traveling hundreds of miles to urban centers for care, while others may not be receiving all the services they need. Some of these problems might be alleviated if rural hospitals and practitioners were better linked to the rural hospitals and practitioners were better linked to the urban centers with specialty and subspecialty clinicial services and where advances in HIV treatment are taking place. For optimal effectiveness, coordinated services need to be planned with appropriate roles for state, regional, and local entities as well as informal rural networks.

CHILDREN AND FAMILIES WITH HIV DISEASE

As HIV spreads rapidly among IV drug users and their sexual and needle sharing partners, entire families are becoming infected and are in need of a full range of HIV health care and support services.

As of March 31, 1990, there were almost 2,200 reported cases of children with AIDS. This number does not include children who are HIV infected, and it is estimated that for every child reported to have AIDS, there are 2 to 10 other unidentified cases. It is estimated that nearly 3,500 children will have AIDS by 1991, and approximately 20,000 will be HIV infected. AIDS will be the fifth

leading cause of death for all children in the next decade and a major cause of mental retardation.

In the adolescent age group, 500 cases of AIDS have been reported. Health care experts assert that this number masks the true incidence of HIV infection in teenagers. Runaway and homeless youth are particularly vulnerable. After fleeing or being ejected from chaotic and often abusive homes, these young people lack access to the traditional sources of positive health messages—the family and the school.

Minority communities have been particularly hard hit. Although blacks and Hispanics represent 15 percent of the population, they comprise 44 percent of all reported AIDS cases—and nearly 80 percent of all women, children, and youth with AIDS.

Poverty, inadequate housing, substance abuse, and other problems make the delivery of health and support services to children and families with HIV disease extremely difficult. Some mothers, sick with AIDS, addicted to drugs, and unable to care for a child with a complex illness, abandon their infants in the hospital. While the care of adults with AIDS is costly, the cost of maintaining these "border babies" is even more costly. In addition, hospitals report losing 5 times more on the care of children with AIDS due to inadequate reimbursement levels.

Children who do leave the hospital require a coordinated system of community-based services. However, many families find that accessing essential services can be a complicated and frustrating process. Women with perinatally infected children, often ill and still addicted to drugs, are not able to function in the role of advocate for their children and have the most limited access to health care for themselves as any group infected with HIV. The availability of health care and support services for HIV infected women and children "under one roof" is critically needed. Essential to its success is a culturally sensitive family centered system of case management.

THE NEED FOR S. 2240

The Committee amendment to S. 2240 represents a comprehensive approach to some of the most pressing problems in health services delivery raised by the HIV epidemic.

To fully understand the need for this legislation, it is essential to remember that HIV disease and AIDS have imposed on our nation's health care delivery system a set of demands that were totally unanticipated a decade ago. In 1980, no federal, state or local health care planning agency could possibly have forseen the introduction of a novel and lethal infectious disease into 20th century society. Indeed, years of intensive clinical and epidemiological research were required to elucidate the full spectrum of HIV disease and to concretely establish that AIDS itself constituted only the final and most acute stage of an infection that had probably already struck one million of our fellow citizens.

Neither health planners nor policy makers knew that—during the decade of the eighties—primary health care providers, support agencies and major medical institutions would suddenly be required to gear up to provide desperately needed services to hun-

dreds of thousands of Americans, most of whom had formerly had little contact with the health care system.

Initially, AIDS struck hardest in a population of previously healthy young men who would normally have seen a doctor only for routine physicals or minor complaints. America's urban gay population found itself plunged wholesale into a type of catastrophic illness which most citizens in western, industrialized nations must not confront until the sixth or seventh decade of life, if ever.

In rapid order, AIDS mysteriously erupted in a widely scattered population of individuals who were likely to be intensive users of medical services: hemophiliacs and blood transfusion recipients. Concurrently—and initially less obviously—the human immunodeficiency virus mustered its attack on intravenous drug using populations whose needle-sharing behavior provided a perfect vector for transmission of the virus. It took several years for the devastating consequences of this latter assault to surface: not only were heterosexual contacts of IV drug users squarely in the path of the deadly virus, so were the future offspring of any infected mother. AIDS thus imposed tremendous new health service demands among drug using populations, their spouses and sexual partners and their children who tended to be concentrated in desperately poor areas of our inner cities. As likely as not, these individuals had absolutely no health insurance, no access to primary care medical or support services, and little or no experience in how to access such services.

Most recently, we have come to recognize the rapid growth of AIDS cases in non-metropolitan and rural areas. The appearance of the disease in sparsely populated areas adds yet another layer of problems to the larger puzzle: how to coordinate and deliver highly specialized clinical and support services needed for the proper management of an HIV-infected individual on a decentralized basis.

If one maliciously set out to formulate a surprise assault to destabilize the healthcare infrastructure of any nation, it is difficult to imagine a more insidious strategy than that which the human immunodeficiency virus has employed in laying siege to the health of the American people. Most devious of all is the extremely long latency period of the disease: ten years or more may be required before sickness becomes manifest in many infected persons.

In sum, our nation's healthcare system was totally unprepared for the advent of AIDS and HIV. Even when the full scope and severity of the epidemic began to be reported in the medical and scientific literature, the planning and funding that would be required to mount an appropriate response lagged.

This legislation represents a unanimous statement by the Senate Labor and Human Resources Committee that comprehensive, forwardlooking action on the part of all levels of government and all sectors of society is required to respond to the care needs generated by the human immunodeficiency virus epidemic.

In fashioning the solutions contained within the legislation, the Committee has sought to balance the differing needs of urban and rural areas, emphasize the crucial role of families in the continuum of care, and ensure that the populations most affected by HIV disease have an active part in developing care and treatment systems. While the bill authorizes major increases in federal funding,

the Committee has also ensured a continuing role for local initiatives in response to local needs.

Title I of the bill addresses the needs of the metropolitan areas where HIV disease is most heavily concentrated. This title establishes an emergency relief program for cities with 2000 or more cases and targets the funds to the most pressing needs of those cities. First, funds are made available for the hospitals and other health care providers that are treating the largest number of low-income persons with HIV disease. Second, grants are provided to develop and support alternatives to inpatient care. These include both case-managed outpatient health and support services and nursing homes or other subacute long-term care facilities.

Title II addresses the HIV epidemic on a national basis, with a special emphasis on the needs of smaller cities and rural areas and on services to families and children with HIV disease. Through formula grants to States and special direct grants to public and private entities, this title helps provide the resources to meet a variety of emerging problems. There are funds to promote development of community-based care systems, in rural as well as urban areas, and to improve the coordination of health and support systems. States may help persons eligible for private health insurance to purchase that coverage, may provide direct support for new HIV drugs and other treatments, and may develop programs to encourage early access to such treatments. Finally, a set-aside of funds for national projects allows for demonstration programs targeted to a variety of populations with special HIV treatment needs, including minorities and the homeless.

Based on its own research conducted over a period of 18 months and on extensive consultation with a wide range of agencies, organizations and individuals which are actively involved in the organization and delivery of HIV health services, the committee reached its decision that the two very different, but complimentary approaches to the funding of HIV care would best address urgent, current needs and encourage action to prepare for future demands.

In essence, the funds authorized in Title I are intended as an emergency bail-out to those urban healthcare systems that are already overloaded by AIDS cases and whose continued functioning is imperiled by the twin epidemics of AIDS and drug abuse. In keeping with other federal emergency management funding interventions, the intention of this authorization is to provide rapid funding to stabilize the nation's hardest-hit health care systems. In the view of the committee, special corrective action is needed in these localities to avert a further deterioration of critical health service delivery to all segments of the resident population—both HIV infected individuals and others.

It is the committee's strongly held belief that funding for AIDS care is not just the responsibility of the federal government. In order to meet the HIV health care challenge that assuredly lies ahead, resources must be contributed by state and local government, private sector health insurors and health maintainance organizations, voluntary and charitable organizations, community support service agencies and by the individuals directly affected by the disease and their families. Only such a partnership of contributors can supply funding adequate to the impending need.

At the same time, the committee has recognized that many hospitals, support service agencies and other care providers at the urban epicenters of the epidemic are currently operating in a crisis modality. In these institutions and organizations, immediate day-to-day service demands are so overwhelming that action to better organize HIV health services cannot possibly command the financial or human resources of the besieged community. Indeed, in the very worst cases, some health care institutions are effectively hemorrhaging money through the inappropriate use of costly acute care medical services. Title I represents an emergency intervention to interrupt this dangerous and costly cycle and enable such providers to normalize operations. In the view of the committee, the need for such federal financial intervention grows more severe with each passing week. Had more resources begun to be invested in HIV care systems beginning in 1986 when the U.S. Public Health Service released its estimate that 1 million or more American were infected with HIV, the total expense AIDS confronting the nation today could have been significantly less. Title I constitutes corrective action and seeks to make up for lost time.

Title II of the legislation channels funds to all 50 states, the District of Columbia and the territories to enable them develop and operate more appropriate systems of HIV health services delivery. The committee has carefully framed Title II to give states maximum flexibility to spend the funds provided in areas of greatest local need. Mechanisms have been included in the title to ensure that interested individuals and organizations are provided with an opportunity to comment on the state's use of these funds and to guarantee that in states with a high incidence of cases that resources reach the local level swiftly.

In making the sensitive decision of exactly how to draw the line between localities that are eligible for Title I emergency funding and those that only will receive financial support from the States through Title II, the committee took pains to obtain detailed guidance from all levels of government, organizations representing both public and private hospitals, state, country and local health officials, community based service providers, voluntary and philanthropic agencies concerned with AIDS, community and migrant health centers, mental health service providers, drug treatment centers, schools of public health, medicine, nursing and social work, HIV infected individuals and their caregivers, and others.

The committee is fully aware that the eligibility cut-off in Title I—namely metropolitan areas with greater than 2000 AIDS cases as of March 31—represents a difficult policy decision. However imperfect, it is actively supported by the National Governors Association, the U.S. Conference of Mayors, the National Association of Counties, the Association of State and Territorial Health Officers, the Pediatric AIDS Coalition, and the more than 140 members of NORA, the National Organizations Responding to AIDS. The unfortunately reality is that in the outyears of this five year authorization, dozens more U.S. metropolitan area will reach the 2000 case threshold, thereby making them eligible for Title I support in all subsequent fiscal years of the authorization. It is the hope of the committee that the full Senate will join in supporting the compro-

mise eligibility definition and direct its energies to obtaining full funding of the authorization during the appropriations process.

Finally, because there is a continuing need for fuller information about HIV treatment needs and the best way of organizing services to meet those needs, Title III authorizes ongoing research on health services delivery for HIV disease.

V. Summary of Committee Substitute for S. 2240

TITLE I—EMERGENCY ASSISTANCE

It is the purpose of this title to provide emergency relief to those metropolitan statistical areas hardest hit by the AIDS public health disaster. Funds are to be used by eligible individual MSAs to:

(a) support hospitals, clinics, community health centers, and nursing/sub-acute care facilities serving a disproportionate share of low-income individuals and families with HIV disease.

(b) provide case-managed community-based outpatient health and support services for the purpose of reducing hospitalization and expediting discharge.

No funds under this Title may be used for renovation or rehabilitation of physical facilities unless the MSA can demonstrate a critical shortage of long-term, sub-acute or congregrate care facilities within the service area. Federal funds used for remodeling must be matched (50/50) by the locality-state with allowance for in-kind contribution.

—50 percent of funds appropriated under this program must be distributed to MSAs with greater than 2000 AIDS cases within 60 days and shall be allotted according to relative number of AIDS cases and per capita incidence within the MSA.

—50 percent of funds shall be awarded by Secretary as supplemental grants to MSAs with greater than 2000 AIDS cases. Such supplemental grants must be distributed within 5 months after funds become available on the basis of need, local investment, potential for immediate utilization, and development of a comprehensive plan for organization and delivery of HIV care, treatment and support services.

In order to receive funds, political subdivisions within each eligible MSA must establish an intergovernmental agreement and an HIV planning council to govern allocation of resources.

Funds must supplement NOT supplant existing state, county, or local funds provided for services to individuals with HIV disease. In addition, funds may not be utilized for any purpose not specifically delineated in statute.

Authorizes $300 million for 1991 and 1992 with such sums as may be necessary in 1993, 1994, and 1995.

TITLE II—COMPREHENSIVE CARE PROGRAMS

It is the purpose of this title to provide for the organization, development and operation of more effective and cost efficient systems for the delivery of essential health care, early intervention and support services to individuals and families with HIV disease in both urban and rural areas. Eligible uses of funds include:

(a) creating and operating local consortia of public and private health and support service entities capable of delivering a comprehensive continuum of care to individuals with HIV disease including children and families in urban and rural areas; a funded consortium must deliver services to the full range of populations with HIV disease within it its service area and must include participation of community organizations with a history of service to such individuals.

(b) delivering outpatient, home health and support services to low-income, medically eligible individuals with HIV disease, including outreach to those living in rural areas;

(c) developing and funding mechanisms to assure continuity of health insurance coverage for individuals with HIV disease;

(d) providing therapeutics determined to prevent serious deterioration of health of individuals with HIV disease and establishing a distribution system that facilitates acccess for such individuals living in rural areas; and

(e) integrating early intervention services with primary care and support services in existing health care settings, with outreach to individuals with HIV disease living in rural areas.

—Up to 10 percent of the funds appropriated under this title may be reserved by the Secretary to directly fund Special Programs of a National Significance for the care of individuals and families with HIV disease and for technical assistance to states.

—The remainder of funds shall be distributed to states based on the number of AIDS cases reported to CDC by the state in the preceeding 24 months as a percentage of all US AIDS cases reported in the same period, with consideration to relative per capita income.

—All states must develop a comprehensive plan for the development and delivery of health and support services to individuals and families with HIV disease in both urban and rural areas.

—All states shall set aside not less than 15 percent of funds for the delivery of health and support services for infants, children, women, and families with HIV disease.

—In states with a significant incidence of AIDS (1 percent or more of the US AIDS cases), not less than 50 percent of funds shall be distributed directly to local entities in areas hardest hit by HIV.

Authorizes $300 million in 1991 and 1992 with such sums as may be necessary in 1993, 1994, and 1995.

TITLE III—HIV HEALTH SERVICES RESEARCH

Directs the Agency for Health Care Policy and Research to evaluate the impact and cost effectiveness of various models of AIDS care including the delivery and financing of health care and support services for infants, children, women, and families with HIV disease.

VI. Section-by-Section Analysis

TITLE I—HIV EMERGENCY RELIEF GRANT PROGRAM

Adds a new Title XXV, Emergency Relief and Care Access Grants, to the Public Health Service Act, and adds Subpart 1, Relief Program, to the new title.

New section 2531 requires the Secretary of Health and Human Services to award emergency relief grants to metropolitan areas that, as of March 31 in any year 1990 through 1994, have reported more than 2,000 AIDS cases to the Centers for Disease Control and meet other requirements.

New section 2532 provides that funds for each eligible area shall be directed to the chief elected official of the city or county in that area whose public health agency serves the greatest number persons with AIDS. That subdivision is required to establish, through agreements with other subdivisions in the area accounting for at least 10 percent of AIDS cases, a mechanism to allocate funds based on numbers of AIDS cases and severity of need. It is further required to establish an HIV health services planning council, including representatives of health care providers, community-based and AIDS service organizations, social service and mental health providers, public health and hospital or health care planning agencies, affected communities, community leaders, and State government. In designating a planning council, priority is to be given to an existing entity with experience in HIV health care planning, if that entity includes representatives of the full range of area service providers. The planning council is to establish priorities for allocation of funds and assess the efficiency of the fund allocation mechanism in rapidly allocating funds to areas of greatest need.

New section 2533 establishes distribution rules for the emergency relief grants. Within 60 days after an appropriation becomes available for each fiscal year, the Health Resources and Services Administration (HRSA) shall award 50 percent of the appropriated funds on the basis of the following formula. Each area's percentage share of the funds is equal to three times its relative cases per area factor, plus its relative cases per area factor times its relative per capita factor, all divided by four. The relative cases per area factor is the ratio of reported cases of AIDS in an eligible area to the total number of cases in all elegible areas. The relative per capita factor is the ratio of per capita incidence of AIDS in an eligible area to the per capita incidence in all eligible areas combined. If the formula results in total grants that are more or less than the amount of the appropriation (that is, if the sum of the percentage shares is greater or less than 100), the Secretary is to make proportionate adjustments in the amounts allocated to each area. The remaining 50 percent of the appropriation for a fiscal year is to be used, within 150 days of the start of the fiscal year, for supplemental grants to eligible areas. Grants are to be on the basis of applications by eligible areas that include a report on the use of the original relief grant; that demonstrates severe need, commitment of local resources, ability to use funds effectively; and that demonstrate that funds will be allocated according to local demographic AIDS incidence, including funds for infants, children, women, and

families with HIV disease. Amounts of supplemental grants are to be determined by the Secretary.

New section 2534 establishes the purposes for which grant funds may be used. First, direct assistance may be provided to public or private nonprofit health facilities that are serving a disproportionate share of low-income persons with HIV disease and are suffering a loss on such care, with priority to be given to facilities that have developed a plan to evaluate HIV services and that have a system to ensure that persons with HIV disease are treated at the most appropriate level of care. Facilities are to use assistance to enhance the quality of HIV services and to deliver comprehensive ambulatory and support services, including case management. Second, grants may be made to community-based agencies that provide case managed outpatient health and support services to persons with HIV disease in order to prevent unnecessary hospitalization and speed hospital discharge. Third, grants may be used to renovate residential or long-term care facilities for persons with HIV disease. If the grantee wishes to use funds for this purpose, it must demonstrate that there is a shortage of such facilities, that it has attempted to identify and remove regulatory barriers to the creation of such facilities, and that it has exercised its authority to insure that persons with HIV disease have access to such facilities. Funds used for renovation must be matched with an equal State or local contribution in the form of funds, inkind services, goods, or real property. Finally, no more than 5 percent of total grant funds may be used for administration and planning.

New section 2535 provides that eligible areas must apply for original and supplemental grants for each fiscal year in a form, and within deadlines, established by the Secretary. Applications must include assurances that funds will be used to supplement and not supplant existing State and local funding for HIV health and support services; that the area has the required HIV planning council and has developed or will develop a comprehensive service plan that is compatible with existing State or local HIV service plans; and that agencies or institutions funded under the grant will participate in any established HIV community-based continuum of care.

New section 2536 authorizes appropriations for emergency relief grants of $300 million in each of fiscal years 1991 and 1992, and of such sums as may be necessary in fiscal years 1993 through 1995.

TITLE II.—HIV CARE GRANTS

Current law.—The Health Omnibus Programs of 1988, P.L. 100–607, authorized formula grants to States for home and community-based health services for persons with HIV during FY 1989 and 1990 only. The Act also authorized three subacute care demonstration projects for fiscal years 1988 through 1991 to provide nursing home care, hospice, or other long-term care to persons with HIV disease, as well as an unspecified number of demonstration projects in the same years to fund counseling and mental health services for a person with HIV disease. Although these are the only specific authorizations for HIV treatment services funding in current law, other broader provisions of the Public Health Service Act

have been used as authority for appropriations of funds for such services. HIV treatment demonstration projects have been funded under general authorizations for the Secretary to carry out health services research. Funds for grants to States to provide HIV therapeutics have been appropriated to the Public Health Emergency Fund authorized by section 319 of the Public Health Service Act; that section authorizes a maximum annual appropriation of $30 million.

The bill.—Adds a new Subpart 2, Care Grant Program, to Part C of Title XXV of the Public Health Service Act, as added by Title I of the bill.

New section 2540 requires the Secretary to make grants to States to improve HIV care in both urban and rural areas.

New section 2541 provides that States are to use HIV care grants for the following purposes: establishment of HIV care consortia to provide a continuum of care in areas most affected by HIV disease; provision of home and community-based HIV care services; development and support of mechanisms to assure continued health insurance coverage for persons with HIV disease; provide HIV therapies that can prolong life or preserve health to low-income individuals; and integrate diagnosis and early intervention with existing primary care and support services. States must use at least 15 percent of grant funds for health and support services to infants, children, women, and families.

New section 2542 establishes detailed requirements for grants by States to HIV care consortia. An applicant must be a consortium of public and private nonprofit health care and support service providers and community-based organizations and must agree to use funds for planning, development, and delivery of comprehensive outpatient and support services for HIV disease. An applicant must provide assurances that it has identified the populations in its area with HIV disease, that its service plan addresses the special needs of those populations, and that it will when practicable establish a single entity in each area served to coordinate care to those populations, unless there are subpopulations with special needs that cannot be adequately addressed by a single entity. Applications must demonstrate that (a) the consortium includes organizations that are representative of the populations to be served and have a record of serving those populations; (b) the consortium's services plan uses existing services before creating new ones, that in urban centers its service area conforms to those of existing delivery systems, that services in rural areas are linked to regional specialty services, and that affected populations participate in assessing services; (c) there has been adequate planning for the special needs of families with AIDS, including family-centered care (defined as a continuum of care for children, women, and families that is based on a partnership of parents, health professionals and the community); (d) the consortium has a mechanism for periodic evaluation of its success and cost-effectiveness; and (e) the consortium will report such evaluations to the State. States are required, in awarding grants, to give priority to existing HIV care consortia, to avoid duplication of effort.

New section 2543 establishes detailed requirements for grants by States for home and community-based services. States may make

grants to provide such services to persons with HIV disease pursuant to a written plan of care developed by a health professional, provide outreach services to such persons (with an emphasis on low-income persons), and coordinate home and community-based services with similar or related services furnished by other providers. Home and community-based health services are defined as including: durable medical equipment, homemaker or home health aide, home intravenous and aerosolized drug treatment or other partial hospitalization services, home intravenous and aerosolized drug therapy (including drugs used in such therapy), routine diagnostic testing in the home, and mental health, developmental and rehabilitation services. Inpatient, nursing home, and other residential long-term care facilities are not included.

New section 2544 provides that States may use grant funds to assist low-income individuals with HIV disease in maintaining a continuity of private health insurance or in participating in a health insurance program established by the State.

New section 2545 establishes requirements for the use of grant funds by States to establish programs to provide therapeutic care. To receive assistance from a State, an individual must have a diagnosis of AIDS or HIV disease and meet the State's definition of a low-income individual. The State is to determine, pursuant to guidelines to be established by the Secretary, the therapies for which payment will be provided. The State must cover both the therapies and any devices needed to administer the therapies, and must provide outreach and an appropriate distribution system to make therapies available in rural areas.

New section 2546 establishes requirements for the use of funds by States for early intervention programs. States may use funds to integrate early diagnosis and intervention services with primary health and support services (including drug treatment and mental health counseling) delivered in existing facilities for the purpose of: (a) providing outreach to persons with HIV disease and health professionals who are unaware of the benefits of early intervention; (b) offering clinical, diagnostic and monitoring services to person with HIV disease; and (c) providing appropriate therapeutics to prolong life or maintain health.

New section 2547 provides that States must apply for grants each fiscal year in a form and within deadlines established by the Secretary, and set forth requirements for applications. An application must contain a description of the intended uses of grant funds, including information on the services and activities to be provided, plans for coordination with other programs to provide a continuum of care, and plans for coordinating with different program options provided for under the grant itself to maximize effectiveness. An application must also include assurances that: (a) the State legislature will conduct hearings on the use and distribution of the grant; (b) the State will to the extent practicable ensure that services under the grant are provided without regard to an individual's ability to pay or current or past health conditions; (c) any charges for grant-assisted services will be pursuant to a public charge schedule, will not be imposed on persons with incomes below 200 percent of the Federal poverty level, and will be adjusted to reflect incomes of persons whose income exceeds that limit; (d) the State

will provide for independent peer review of the quality and appropriateness of grant-assisted services; (e) the State will cooperate in Federal research programs (described below); (f) the State will maintain State spending for HIV-related health and social services at a level at least equal to the State's average spending in the 2 years preceeding the fiscal year covered by the application; (g) the State will not use grant funds to pay for services that are reimbursable under other public health coverage programs; and (h) the State will establish a comprehensive service plan based on the needs assessment required under section 2542. If a State demonstrates in its application that cases of AIDS among infants, children, women, and families account for less than 15 percent of all AIDS cases in the State, the Secretary may waive the requirement that 15 percent of grant funds be used to serve these groups, and permit the State to allocate funds in accordance with the State's own demographic breakdown of cases.

New section 2548 requires the Secretary to use up to 10 percent of funds appropriated for the HIV Care Grants program to provide technical assistance and to establish a Special Projects of National Significance program. The Program would award direct grants to States, localities, or community-based organizations for HIV treatment demonstration programs, to test innovative models of AIDS care than can potentially be replicated elsewhere. Among the possible projects to be funded under the Program would be: combined HIV/drug abuse treatment programs, incentives for providers to treat low-income HIV patients, support for informal and family-based care networks in the minority community, development of service resources in rural areas and on Indian reservations, and delivery of services to the homeless and to prisioners.

New section 2548 also establishes the formula under which such appropriated funds are to be allocated among States and the rules for each State's allocation of the funds it receives. A distribution factor is to be established for each State, equal to the product of (a) the number of new reported and confirmed AIDS cases in the State in the 2 most recent fiscal years and (b) the cube root of the ratio of the United States average per capita income and the State's average per capita income during the most recent period for which data is available. In the case of a territory, the distribution factor is equal to the number of new reported and confirmed AIDS cases in the territory in the 2 most recent fiscal years. Each State's (or territory's) share of the total amount appropriated during a fiscal year is determined by multiplying the total appropriation by the ratio of the State's distribution factor to the sum of all States's distribution factors. The minimum amount allocated to a State or the District of Columbia is $100,000; there is no minimum for the territories. If a State accounts for 1 percent or more of the AIDS cases reported to Centers for Disease Control, it must use at least 50 percent of grant funds for comprehensive care consortia in the areas with the most persons with HIV disease; in allocating these funds, the State is to take into account any funds received by an area under the program of emergency grants to cities established under Title I. A State may use no more than 5 percent of its total grant for planning and evaluation, and no more than 5 percent for administration. The State must allocate and make available 75 per-

cent of its grant funds within 120 days after receiving them; within this period, the State is to invite public comment on uses for the funds. Any part of the 75 percent of grant funds not obligated within in 120 days is to be recaptured by the Secretary and allocated proportionately to other States.

New section 2548 also defines the term "territory of the United States" to include the Virgin Island, Guam, American Samoa, the Commonwealth of the Northern Mariana Islands and Puerto Rico.

New section 2549 authorizes appropriations of $300 million in each of fiscal years 1991 and 1992, and such sums as may be necessary in fiscal years 1993 through 1995.

New section 2550 defines a State as including (unless otherwise specified) the 50 States, the District of Columbia, the Virgin Islands, Guam, American Samoa, the Northern Mariana Islands, and Puerto Rico.

TITLE III—HIV DISEASE HEALTH SERVICES

Research, evaluation, and assessment

Section 301. Purpose. Provides that the purpose of Title III is to develop information rapidly on the effectiveness of HIV health service delivery and financing systems.

Section 302. Research, Evaluation, and Assessment Program. Requires the Secretary to establish a research program under the Agency for Health Care Policy and Research, using appropriate experts to: (a) compare the impact and cost-effectiveness of different models for organizing HIV and AIDS health care delivery; (b) review the relative contribution of different public and private payers to HIV health care financing, (c) assess how point-of-entry procedures for obtaining HIV health care treatment and support services impacts the cost, quality and outcome of care, and the extent to which quality, cost and outcome of this care can be related to different sources of payment for services and treatment; (d) report on financial and other barriers to HIV care, with emphasis on the effect of disadvantaged status on service delivery; (e) report on unmet health care needs for persons with HIV disease, and (f) assess models for delivery of services to infants, children, women, and families with HIV disease. The Secretary is required, within 2 years after enactment, to submit a report on the results of the research program to the House Committees on Energy and Commerce and Ways and Means and the Senate Committees on Labor and Human Resources and Finance.

VII. Committee Views

TITLE 1

Through Title I of the legislation, the committee intends to send urgently needed financial relief to health and service providing agencies and institutions in those areas of the nation that have been struck most severely by the HIV epdidemic. It is the committee's conclusion that institutions and agencies serving large numbers of low-income persons with AIDS over a period of several years have been exposed to potentially crippling economic and operational burdens.

A chronic and protracted lack of adequate reimbursement for the intensive services that are required for the care, treatment and management of patients with HIV has resulted in the overall deterioration of the ability of such hard-hit institutions and agencies to effectively respond to the needs of their catchment areas and communities. It is this cummulative drain on institutional and organizational resources that imperils the healthcare infrastructure in areas with the largest number of AIDS cases. While our society has collectively invested huge sums to develop and operate a network of care providing agencies that will be capable of responding to the emergency medical needs of the American people, AIDS has exposed organizations at the epicenters of the epidemic to protracted emergency stress for a period of years. Normally, such intense systemic demands are experienced only in times of a natural or manmade disaster such as fire, flood, or earthquake. AIDS have steadily imposed mounting pressures on urban health institutions and agencies for a period of years.

The committee therefore intends that Title I emergency relief funds go to those frontline care providers which have been most severely worn-down by the cummulative strains created by service delivery to a large number of low-income AIDS patients.

The committee is aware of the seemingly overwhelming problems facing care institutions in areas with the greatest number of cases. The committee intends that Title I funds be applied as rapidly as possible to ameliorate the most serious problems and to help restore operations to a more normal basis. Among the problems of greatest concern to the committee are emergency room overcrowding and protracted delays in admission to acute care hospital beds, a lack of trained medical and support personnel to deliver in-patient services, a lack of critical support services in the areas of outpatient and ambulatory medical services, psychological, mental health and social work services, case management, transportation, and discharge planning. The committee is equally concerned that resources be made available to increase the availability and accessibility of step-down care alternatives. There are a wide range of *potential* alternatives to in-patient hospitalization for patients with HIV disease, ranging from nursing home and hospice care, to medically supported residential facilities, to home care that is supported by community-based essential support services. As explained in greater detail below, the committee intends that all sectors of the care providing community as well as the populations most directly affected by the HIV epidemic take an active role in each eligible area in deciding where Title I funds are most badly needed and can be most effectively deployed. This will require careful balancing of many competing demands within each community.

The overall guidance of the committee to areas receiving emergency support is that Title I funds be used both to reduce institutional or organizational stresses resulting from AIDS overload and to improve the quality and availability of those out-of-hospital medical and support services which can contribute to reduced utilization of in-patient hopitalization. Given the increased number of individuals who will develop serious illness due to HIV disease during the period of this authorization, continued use of acute-care

hospital beds for custodial and long-term care is not a realistic policy option.

This Committee intends that the grants awarded under section 2532 will be made to the chief political officer of the city or urban county which administers the public health agency serving the greatest number of people with AIDS in the eligible area. In those cases where a political subdivision does not elect a single chief elected official, but rather a board of elected officials, the board shall fill the role of the chief elected official.

The chief elected official established by the bill has two primary responsibilities other than those related to the accountability functions normally established. These are to enter into intergovernmental agreements to distribute funds to other eligible political subdivisions with the area and to designate an HIV health services planning council.

Intergovernmental agreements are required to maximize the utility of federal assistance by ensuring coordination of all health and social service delivery systems in the eligible area. The committee requires that such agreements be established for each political subdivision that has more than 10 percent of the total number of AIDS cases reported by the eligible area and that has jurisdiction over any health and support service delivery system. These agreements should be in accordance with the assurances required in the legislation.

The HIV Planning Council will be established by the chief elected official to whom the federal assistance grant is awarded. The Committee intends that the representatives of the service delivery system delineated in the legislation will be appointed to the council by the chief political official. The committee expects that people with HIV and AIDS will be incorporated into the planning councils. The committee also intends that the planning councils shall include representatives of state government.

The committee expects that any existing entity with demonstrated experience in assessing needs and planning services for individuals and families with HIV disease will serve as the foundation for the development of the Planning Council. In particular, the committee intends that existing HRSA AIDS Service Demonstration Projects be given an active role in the planning process. The committee expects that any existing entity selected to serve as the area planning council will adhere to the provisions of this bill and that additional council members will be added to reflect the full geographic area and the full range of populations affected by AIDS within such area.

The role of the HIV health services planning council is to establish priorities for the allocation of emergency relief. The committee recognizes the ultimate spending authority and fiduciary responsibility of the officials. However, the Committee intends that the planning council will be given full authority to develop a blueprint for action that will be implemented by the chief elected official.

COMMITTEE VIEWS: TITLE II

Section 2541. General uses of grants

The Committee recognizes that the health care and support service needs of individuals and families with HIV disease vary considerably from community to community and from state to state. A variety of factors contribute to this diversity including the local epidemiology and demographics of those infected, the health care infra-structure currently in place, and the nature of eligibility requirements and extent of reimbursement of the state Medicaid program. In order to allow for the flexibility necessary to design programs to meet unique needs and circumstances, the Committee has utilized the state block grant approach.

It is the Committee's belief that the statutorily delineated uses of funds provide a framework within which each state and local community can improve the availability, quality, and organization of services to individuals and families with HIV disease. From high incidence urban centers to small towns and rural areas, the state grant program contains a range of options which can be molded to appropriately respond to the epidemic.

It is the Committee's intent that the states use these dollars for only those purposes specifically defined in this statute. However, the Committee does not require that each state implement all five of the eligible programs. In addition, the state need not set up separate and distinct programs for infants, children, women, and families with HIV disease in order to satisfy the set-aside requirement. Rather, the state must be able to demonstrate that 15 percent of the funds allocated were utilized to provide health and support services to these populations.

Section 2542. HIV care consortia

In developing community-based care consortia, the Committee intends to: (1) support and/or facilitate the organization of systems of care for individuals and families with HIV disease through the development of a coalition (public-private partnership) of essential service providers and community-based organizations; (2) identify gaps in service needs and develop a comprehensive continuum of services to meet those needs; (3) promote coordination and integration of community resources; (4) ensure continuity of services through effective case management; and (5) provide cost effective alternatives to hospitalization.

The Committee intends that the consortia consist of the public and not-for-profit providers of essential health and support services for persons with HIV disease. The Committee assumes that this will certainly include local health and social service departments, AIDS service organizations, community health and mental health centers, community-based and university-based HIV clinical trial operators, hospital outpatient and other ambulatory clinics, visiting nurses and other home health care providers, and a vast array of others agencies and organizations depending on local demographics of AIDS. The Committee recognizes the critical role that can be played by people living with HIV disease in defining gaps in essential services and assisting in the development of programs to meet

their needs, and therefore intends that they be active participants in the consortia.

It is not the intent of the Committee that the consortia needs to be legally incorporated but each participant should commit to contribute resources such as time, personnel, and in-kind and/or fiscal support as appropriate. It is also not the intent of the Committee that the consortia itself become a primary provider of essential services but rather that it utilize the consortia to coordinate and expand existing services and then to identify remaining gaps. Once needed services are identified, the consortia should utilize the resources made available under this section to create or reimburse such services through the consortia participant best able to accomplish the goal. This means that the funds should be channeled through the organization with the most experience with the identified population and type of service needed. In this way, the consortia does not build a new and separate system but enhances the capacity of an in place network.

It is the Committee's intent that in metropolitan areas, the consortia service delivery area parellel the existing local health and social services area, to the extent practicable, in order to maximize the potential for coordination. In addition, the Committee expects that the consortia will address the special care needs of each of the populations and subpopulations that have been affected by HIV within the service area—including gay and bisexual men, intravenous drug users, hemophiliacs, recipients of blood transfusions, women, infants, children, adolescents, and entire families. This is not to say that all individuals and families with HIV disease should be served by a single program. Rather, the Committee merely intends to charge the consortia with the responsibility to see to it that services are made equitably available and accessible to all individuals affected by HIV.

It is the Committee's intent for states to give priority to existing HIV care consortia and demonstration projects where they exist so as to build on a base of experienced providers and avoid duplication of services within an area. Among consortia to be given priority are the federally funded health Resources Services Administration AIDS services demonstration projects and the Robert Wood Johnson care networks. Initiated in 1986, HRSA has sponsored 26 adult and 13 pediatric demonstration programs for persons with HIV disease. Originally targeted to communities with the largest caseloads, the number of grantees has increased each year as the consortia model has favorably impacted on the coordination of a continuum of care and provided alternatives to inpatient hospital care. The flexibility of the projects to respond to local service demands and needs was highlighted in an evaluation submitted to HRSA by SysteMetrics in 1989. Recommendations were made for continued federal support of existing projects, and expansion of these model programs to other localities.

The Committee has witnessed the success of community-based organizations with a strong commitment to, and history with, particular subpopulations—and encourages consortia to build on these trusting relationships. This allows for programs which are culturally, socially, and linguistically sensitive and appropriate. The Committee believes that the a well functioning and frequently utilized

essential service system is one which empowers people with HIV disease and their caregivers and minimizes potential for alienation.

The Committee heard a great deal while in rural Georgia about the need for coordinating and maximizing essential services for individuals and families with HIV disease living outside of urban centers. Because the HIV epiedmic has more recently reach into rural communities, considerable hesitation in dealing with it remains. The Committee was told by one rural physician that the best bet for receiving services for a person with AIDS living in a rural area would be to go to prison. Therefore, the Committee is committed to facilitating the development of linkages between the local, regional, and state providers in order to improve access to essential services for individuals and families living in rural areas.

Since the Committee acknowledges that many rural communities will not reach the critical mass of individuals with HIV disease or services providers necessary for comprehensive programs, a case managed regional approach has been incorporated. The Committee recognizes the need to involve the local community and encourages the development of regional consortia that building on local informal support networks and allow for local autonomy/control. This approach seems to facilitate better coordination of efforts, more efficient use of resources, greater exchange of information, and broader community support.

The Committee envisions a multi-tiered but coordinated system of service delivery with certain highly specialized services in a large city with a major medical establishment, acute hospital care, hospice care, and nursing home care at the regional level, and visiting nurse/home care, social support, outreach, and respite care/informal day treatemnt at the community level. A state that chose to implement a series of regional consortia could make use of roving specialists who could provide enhanced services at the regional level—either on an on-call basis or with regular schedules.

The Committee strongly believes that the cooperation and coordination facilitated through the development and operation of community-based consortia will improve the quality, availability, and organization of essential health and support services for individuals and families with HIV in urban and rural areas. It is the Committees intent to maximize the percentage of dollars used for consortia for the delivery of services that would not otherwise be available. While the Committee acknowledges the important of needs assessment and service planning, we are aware that, particularly in high incidence urban areas, considerable planning has taken place and what is desperately needed are the resources to imlement essential programs. It is the Committee's intent that these funds represent the long awaited service dollars.

Section 2543. Home care

As the number of AIDS cases has increased, it has become clear that concentrating patients with AIDS in a few institutions is no longer possible or desirable. For this reason, the Committee wishes to encourage and support increased involvement of community physicians in the care of people with AIDS and related illnesses.

The Committee believes that there is a great need for the increased availability of home and community based services in order

to provide appropriate care for people who have AIDS. Hospital care for such individuals may actually place them at higher risk because of the danger of nosocomial infection. In many cases, hospital care is poor substitute for medical, nursing and support care services (homemaker services, meals on wheels, psychosocial support counseling) which are not available in the community. In addition, hospital care is generally far more costly. The Committee took careful note of testimony which compared the relative cost of providing a day of medical care in the hospital to the cost of providing a day of appropriate care at home. In New York City, the difference is ten fold, with the cost of a day of care in the hospital averaging about $800 and the cost of a day of care at home averaging about $80.

The Committee has also received testimony which compared the average life-time cost of providing care to AIDS patients in a city like San Francisco where there are extensive home and community-based medical and medical support services and a city like New York where there are far fewer support services available. Estimates of life time costs varied by a factor of three, with much less spending where support services were available.

The Committee intends that home and community-based services established or supported under this provision will consist of team-oriented, managed care with coordination of the full spectrum of home and community based services which are necessary to maintain ailing individual outside the hospital. This managed care approach will enable the team to pay for other care and treatment services deemed appropriate. The Committee is specifically concerned about the availability of mental health and psychosocial developmental and rehabilitative support services. Factors which heighten the need for such services are involvement of the central nervous system in AIDS infection, with resultant mental retardation and motor dysfunction in children. In addition, infection with the etiologic agent for AIDS produces complex social consequences which produce added distress for those who suffer the illness. The Committee expects that the funds will be used to provide those home and community based services that are widely recognized as necessary for the proper care (including medical care, mental health care, psychological and material support, meals on wheels, homemaker services, etc.) and support needs of such patients. The Committee anticipates that his effort will reduce the need for hospitalization.

Section 2544. Continuum of health insurance coverage

The Committee intends that funds allocated under Section 2544 may be used to pay private insurance premiums for individuals with HIV disease who are eligible for continued health insurance coverage under the provisions of the Consolidated Budget Reconciliation Act of 1985, as amended by the Omnibus Budget Reconciliation Act of 1989 (provisions collectively known as "COBRA").

Under COBRA, persons who are terminated or who elect to leave their employment may continue their employer-sponsored group insurance coverage for a period of 18 months. Premiums for such coverage may not exceed 102 percent of the group rate. As to persons with HIV disease, COBRA permits the extension of insurance bene-

fits for up to 29 months and limits the premium to 150 percent of the group rate. These rules are designed to maintain on private insurance plans persons who have medical conditions that limit or prevent their employment, thereby minimizing dependence of Title XIX of the Social Security Act (Medicaid).

The use of government funds to pay private insurance premiums can substantially reduce Medicaid expenditures. Michigan, New York and Washington have used State Medicaid dollars to pay private insurance premiums, resulting in dramatic cost savings.

The Committee notes that the Congressional Budget Office has projected a cost savings for the Medicaid program nationwide if federal subsidies are used to pay COBRA premiums.

The Committee intends that funds provided under Section 2544 to pay insurance premiums be used in such a manner so as to minimize costs to the Medicaid system and to provide individuals with health insurance coverage at the earliest stages at which Funds allocated under Section 2544 may, at the States' option, also be used to pay premiums for or make contributions to State-sponsored health insurance plans, including risk pool programs. In developing such a pooled-risk approach, the committee believes that certain states may choose to explore new partnership models that more equitably spread the risk and expense of AIDS and HIV care across the public and private sector.

Section 2544 does not affect existing COBRA regulations and is not intended to increase the burden of private employers who provide health insurance plans to their employees.

Section 2545. Provision of theraputics

The Committee intends that funds be used to provide financial assistance to low-income individuals with HIV disease to pay for drugs that have been determined by the FDA to prolong life or prevent serious deterioration of health. When the Committee states that the Secretary shall issue guidelines concerning which therapies can be reimbursed, the Committee intends that the FDA approval process act the Secretary's proxy.

It is the Committee's desire to use these dollars for those individuals who would other wise be unable to benefit from theraputic intervention. Therefore, the Committee intends that funds be used to assist those eligible individuals who are not covered by the state Medicaid program or other third party payors, or whose state Medicaid program does not provide coverage for the needed therapy. These funds must be used to supplement and not supplant any other state, local, and other non-federal funds that would, in the absence of this program, be used for the costs of HIV related drugs. As stated in the statute, for purposes of eligibility for assistance, the term low-income will be defined by the state.

Currently, the grant funds that operate the AIDS Drug Reimbursement Program may be used to pay for the cost of the drugs including a reasonable dispensing fee and may not be used for administrative costs associated with the program. The Committee wishes to continue to utilize these dollars for life saving theraputics with one caveat. The committee is committed to increasing the health care options of individuals with HIV disease living in rural areas. Therefore, the Committee has authorized the use of funds

for outreach to those individuals who may not know of their eligibility or of the benefits of theraputic intervention.

The Committee has heard from individuals living in rural areas that some states have implemented a drug reimbursement program based in a single metropolitan area. Individuals with HIV disease living in rural areas are then expected to travel, sometimes several hundred miles, in order to receive much needed therapies. The Committee intends that these dollars help to make theraputics more readily available to individuals living in rural areas through an accessible distribution system.

Section 2546

It is the Committee's intention that States be able to use Title II funds to expand and develop programs for early diagnosis and early treatment interventions in people with HIV disease. In the use of funds for this purpose, priority should be given to existing primary care facilities, including those operated with public funds. It is not the Committee's intention to stimulate the development of an entirely new network of treatment facilities, but to encourage existing primary care providers to develop enhanced capacity to deliver services and to conduct outreach to health professionals in their service area. Emphasis on outreach and education should be given to populations that are underserved with respect to access to HIV clinical services, diagnosis, medical follow-up and treatment, including minorities.

The Committee intends that states make a particular effort to reach non-urban and rural populations that are affected by HIV and their care providers. Among the services to be funded under this section are early diagnosis including laboratory tests, physical examinations, other diagnostic procedures, routine medical monitoring and follow-up, and other clincial services which may be necessary to maximize the health or prolong the life of an infected individual. In addition, funds may be used to purchase or otherwise obtain therapeutics that, in the opinion of the patient's primary care physician, will help an HIV infected individual survive longer or will prevent serious deterioration of health.

Section 2547. Children and family set-aside and waiver

Because of the need for a special emphasis on health care and suport services for children, adolescents, women and families with HIV disease the bill provides that not less than 15 percent of a State's funds be allocated to providing services for this population. However, the bill also provides a waiver from this requirement for those States that can demonstrate that the number of cases of AIDS among infants, children, women, and families is less than 15 percent.

The Committee does not intend that the provision for a waiver releases the States from their responsibility to provide specialized services for this population, but they are permitted to allocate their resources in relation to the local demographic incidence of AIDS in the State. For example, if the incidence in the State is eight percent, then the Committee expects the States will use eight percent of its HIV care grant funds to provide services to infants, children, women and families with HIV disease.

The Committee expects the process of applying and granting a waiver should not be burdensome to either the States or the Federal government. The Committee would find it acceptable to base the waiver on something as simple as a statement by the States of the incidence of AIDS cases in this population reported to the Centers for Disease Control for inclusion in the HIV/AIDS Surveillance Report for April of each year.

Section 2548. Distribution of funds

The Committee substitute allows the Secretary to retain up to 10% of the Title 2 funds for Special Projects of a National Significance. It is the intent of the Committee that these funds be used to demonstrate the effectiveness of various different innovative aspects of the delivery of health and support services to individuals and families with HIV disease.

The remaining 90% of available funds will available to all states on the basis of a formula grant for the purposes delineated in the statute. The Committee has based the formula on both recent incidence of AIDS and per capita income. It is the Committee's intent that by using recent incidence, the dollars will continue to follow the epidemiology of the epidemic. In addition, per capita income has been added as a factor because of the Committee's belief that the poorer states experience a more serious underreporting problem and therefore their AIDS population has been underestimated. The Committee beliefs that this adjustment assists in directing the much needed resources to where there are people living with AIDS in need of services.

The Committee intends, that states with a significance of AIDS, must utilize 50% of funds made available under this Title for the creation and operation of community-based consortia as defined in Section 2542. For the purposes of this Act, states with a significant incidence are those with more than 1% of the total number of US AIDS cases. The state shall use these consortia funds in those areas of the state that have been the hardest hit by the HIV epidemic. The Committee believes that these areas are both urban and rural. The Committee wants to make special note of, and give priority to, those cities with more than 1,000 diagnosed cases of AIDS but which do not yet qualify for disaster relief. These areas have a disaster that is unfolding daily and the Committee wants to be sure that they receive the relief that they need under this Title 2.

VIII. Committee Action

S. 2240 was brought for markup at the Committee on Labor and Human Resources executive session on April 4, 1990. The committee voted to adopted and favorably report S. 2240, as an amendment in the nature of a substitute, by a roll call vote of 16–0.

At that time, the Committee dedicated S. 2240 to Ryan White and people with AIDS everywhere.

IX. Regulatory Impact

The Committee has determined that there will be a diminimus increase in administrative burden imposed by this legislation.

Dollars appropriated under this Act are intended to be used for the development and delivery of essential health and support services and do not reuqire new federal regulations.

The Committee intends that, to the extent feasible, the Health Resources and Services Administration (HRSA) make use of the program guidance currently in effect for the unauthorized AIDS service demonstration projects, early intervention demonstration projects, and the drug reimbursement program which have been incorporated herein to implement this authorizing legislation. In addition, the AIDS home health care services state grant program specifications authorized in Public Law 100-607 have been incorporated into this legislation in order to reduce the regulatory burden on both federal and state government.

To the extent that this legislation mandates specific administrative procedures as well as planning and evaluation activities, sufficient monies have been set-aside for this purpose.

The Department of Health and Human Services has expressed concerns about the administrative burden resulting from the 15 percent set aside in the state grant program for children, women, and families. The Department believes the majority of states will seek a waiver of this requirement thereby creating a burdensome process. The Committee believes the Secretary has the capacity to streamline such a procedure in order to minimize the regulatory burden.

X. Cost Estimates

U.S. Congress,
Congressional Budget Office,
Washington, DC, April 11, 1990.

Hon. Edward M. Kennedy,
Chairman, Committee on Labor and Human Resources,
U.S. Senate, Washington, DC.

Dear Mr. Chairman: The Congressional Budget Office has prepared the attached cost estimate for S. 2240, the Comprehensive AIDS Resources Emergency Act of 1990, as ordered reported by the Senate Committee on Labor and Human Resources on April 4, 1990.

If you wish further details on this estimate, we will be pleased to provide them.

Sincerely,

Robert D. Reischauer, *Director.*

Attachment.

CONGRESSIONAL BUDGET OFFICE—COST ESTIMATE

1. Bill number: S. 2240.

2. Bill title: Comprehensive AIDS Resources Emergency Act of 1990.

3. Bill status: As ordered reported by the Senate Committee on Labor and Human Resources on April 4, 1990.

4. Bill purpose: To amend the Public Health Service Act to provide grants to improve the quality and availability of care for individuals and families with HIV disease, and for other purposes.

5. Estimated cost to the Federal Government:

[By fiscal years, in millions of dollars]

	1991	1992	1993	1994	1995
Estimated authorization levels					
HIV emergency relief grants	300	300	312	325	338
HIV care grants	300	300	312	325	338
HIV health services research	3	3			
Total estimated authorization levels	603	603	624	650	676
Estimated outlay levels:					
HIV emergency relief grants	252	300	310	323	336
HIV care grants	165	264	307	318	330
HIV health services research	3	3			
Total estimated outlay levels	420	567	617	640	666

Details in this table may not add to totals due to rounding.

The costs of the bill fall within budget function 550.

Basis of estimate: S. 2240 would authorize the Secretary of Health and Human Services (HHS) to award emergency relief grants to metropolitan areas that have more than 2000 acquired immunodeficiency syndrome (AIDS) cases per year as reported by the Centers for Disease Control. Localities would use the grants to make direct financial assistance to not-for-profit entities providing care to a disproportionate share of low income individuals with the human immunodeficiency virus (HIV). The bill provides an authorization level of $300 million in each of fisal years 1991 and 1992 and such sums as may be necessary in fiscal years 1993 to 1995 for the emergency relief grants. The 1993 to 1995 levels were estimated by increasing the 1992 authorization for projected inflation.

The bill also would require the Secretary of HHS to award grants to states for improving the quality of treatment and support services for individuals with HIV. The states would use their allotments to: establish HIV care consortiums; provide home- and community-based care services; assure the continuity of health insurance coverage; provide therapeutic treatments; and to integrate early diagnosis and intervention services with primary health care for individuals with HIV. The bill provides an authorization level of $300 million in each of fiscal years 1991 and 1992 and such sums as may be necessary in fiscal years 1993 to 1995 for these grants. The 1993 to 1995 levels were estimated by increasing the 1992 authorization for projected inflation.

S. 2240 would require the Agency for Health Care Policy and Research (AHCPR) to establish a program to research and develop: a comparative assessment of the cost-effectiveness of models for delivering AIDS and HIV health care; a review of major health services financing mechanisms; an assessment of how point-of-entry procedures for obtaining HIV health care treatment impact the cost and quality of the care; a report of the significant barriers that limit the delivery of quality health services to persons with HIV; a summary report concerning the unmet care needs of persons with HIV; and a review and assessment of models for delivery of health services for children, women and families with HIV. A comprehen-

sive report containing the reports, evaluations and assessments would be submitted to Congress not later than two years after enactment. The bill provides no authorization for these provisions. According to AHCPR, it would cost approximately $3 million in both fiscal years 1991 and 1992 in order to complete the report.

This estimate assumes that all authorizations are fully appropriated at the beginning of each fiscal year. Outlays are estimated using spendout rates computed by CBO on the basis of similar program data.

6. Estimated cost to state and local government: Localities disproportionately affected by HIV could use amounts of their emergency relief grants for renovating facilities for the treatment of individuals with HIV only if they match each $1 of federal funds with $1 of state or local funds. The state or local share could be in the form of services, goods, or property.

7. Estimate comparison: None.

8. Previous CBO estimate: None.

9. Estimate prepared by: Karen Graham (226–2820).

10. Estimate approved by: C.G. Nuckols, for James L. Blum, Assistant Director, for Budget Analysis.

XI. Changes in Existing Law

S. 2240 changes existing law by amending Title XXV. of the Public Health Services Act (42 U.S.C. 300ee et seq.) by adding at the end a new part.

In creating a new Part C—Emergency Relief and Care Access Grants, this legislation provides specific authority for a variety of programs currently operated under the general authority of the Department of Health and Human Services.

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